

# CEREDIH - French National Registry for Primary Immunodeficiencies

Head :Mahlaoui Nizar, CEREDIH Centre de référence Déficits Immunitaires Héritaires

Fischer Alain, CEREDIH Centre de référence Déficits Immunitaires Héritaires INSERM U768  
(Développement normal et pathologique du système immunitaire) Fondation Imagine

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## General

### Identification

Detailed name French National Registry for Primary Immunodeficiencies

Sign or acronym CEREDIH

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL n°1165361 (28/04/2006)

### General Aspects

Medical area Immunology  
Rare diseases

Health determinants Genetic

Others (details) all pathologies characterized by qualitative and/or quantitative abnormalities of the immune system, bringing about a increased susceptibility to infections, autoimmunity and cancer

Keywords primary immunodeficiency, rare disease, immune system, autoimmunity, genetic anomaly, infection, cancer

### Scientific investigator(s) (Contact)

Name of the director Mahlaoui

Surname Nizar

Address Groupe Hospitalier Necker-Enfants malades - CEREDIH Carré Necker - Porte N3 - 1er étage - 149 rue de Sèvres - 75743 Paris Cedex 15

Phone + 33 (0)1 44 49 46 22

Email	nizar.mahlaoui@nck.aphp.fr
Unit	CEREDIH Centre de référence Déficits Immunitaires Héréditaires
Organization	APHP, Groupe Hospitalier Necker enfants

Name of the director	Fischer
Surname	Alain
Address	Groupe Hospitalier Necker-Enfants malades
Phone	+ 33 (0)1 44 49 46 22
Email	alain.fischer@nck.aphp.fr
Unit	CEREDIH Centre de référence Déficits Immunitaires Héréditaires INSERM U768 (Développement normal et pathologique du système immunitaire) Fondation Imagine
Organization	APHP

## Collaborations

## Funding

Funding status	Mixed
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Details	Ministry of Health, Co-Funding by pharmaceutical firms and Patients' association donations
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## Governance of the database

Sponsor(s) or organisation(s) responsible	APHP
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Organisation status	Public
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## Additional contact

## Main features

## Type of database

Type of database	Morbidity registers
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Database recruitment is carried out by an intermediary	A selection of health institutions and services
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Database recruitment is carried out as part of an interventional study

No

## Database objective

### Main objective

The main objective of the French national registry for primary immunodeficiency (PID) is to list all patients - living or deceased - who are suffering or have suffered from these diseases in France so as to estimate and monitor their prevalence, incidence, demographic characteristics, age at diagnosis, period of time between first symptoms and diagnosis, survival and mortality.

### Inclusion criteria

Alive and deceased patients with primary immunodeficiency in France

## Population type

### Age

Newborns (birth to 28 days)  
Infant (28 days to 2 years)  
Early childhood (2 to 5 years)  
Childhood (6 to 13 years)  
Adolescence (13 to 18 years)  
Adulthood (19 to 24 years)  
Adulthood (25 to 44 years)  
Adulthood (45 to 64 years)  
Elderly (65 to 79 years)  
Great age (80 years and more)

### Population covered

Sick population

### Gender

Male  
Woman

### Geography area

National

### Detail of the geography area

Metropolitan France and overseas departments/territories

## Data collection

### Dates

#### Date of first collection (YYYY or MM/YYYY)

01/2006

## Size of the database

#### Size of the database (number of individuals)

[1000-10 000] individuals

Details of the number of individuals	664 en 2006, 1370 en 2007, 815 en 2008 et 411 en 2009, ce qui faisait un total de 3360 cas au 1er janvier 2010 Nombre de nouveaux cas attendus par an dans cette population estimé à : 160 (fréquence : 1/5000 et 800 000 naissances/an) 664 in 2006, 1,370 in 2007, 815 in 2008 and 411 in 2009, making a total of 3,360 cases as at January 1st 2010. Number of new cases expected per year in this population estimated to be: 160 (frequency: 1/5,000 and 800,000 births/year)
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## Data

Database activity	Current data collection
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Type of data collected	Clinical data Paraclinical data Biological data Administrative data
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Clinical data (detail)	Direct physical measures
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Paraclinical data (detail)	Imaging, Pathology
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Biological data (detail)	CBC, Ig quantitation assay, Lymphocyte phenotyping, Genetic analyses
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Administrative data (detail)	Follow-up hospital, Contact physician, Competence center, Patient consent, Place of residence
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Presence of a biobank	No
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Health parameters studied	Health event/morbidity Health event/mortality Quality of life/health perception
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## Procedures

Participant monitoring	Yes
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Details on monitoring of participants	Case follow-up is carried out once a year.
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Links to administrative sources	No
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## Promotion and access

### Promotion

Link to the document	<a href="http://www.ceredih.fr">http://www.ceredih.fr</a>
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### Access

Terms of data access (charter for data provision, format of data, availability delay)

Annual national meeting, website, mail contact for CEREDIH manager  
If a team wished to work on the registry's data, the project would have to be submitted to the CEREDIH scientific advisory board.

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only